Inflammatory Bowel Disease Research Priorities:

Applying an internationally adopted method to identify the top 10 research priorities of people living with IBD, their carers and healthcare professionals in Australia

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Background

An estimated 100,000 Australians live with inflammatory bowel disease (IBD), one of the highest prevalence in the world. There is no cure for IBD and the cause is unknown. There is a strong need for more research in IBD as treatment is variable, burden of disease is high in Australia, and incidence is increasing. [1-3]

Project aim

Crohn's & Colitis Australia (CCA) in collaboration with The James Lind Alliance (JLA), of the UK led a process that aimed to engage people with IBD, carers and healthcare professionals (HCPs) to identify their unanswered research questions and prioritise the top 10 evidence uncertainties for IBD in Australia.

Project relevance

Consumers and HCPs provide high quality and meaningful contributions to the design of research as they ensure relevance to the community, have direct lived experience, and can provide insights on missing evidence. [4]

The top 10 priorities will provide evidence to guide policy, researchers and research funders to focus on the most urgent and relevant needs of consumers and HCPs for IBD.

Method

This project adapted the well-established method of the JLA which follows a step-by-step guide to develop credible and useful outcomes.[5] The protocol, tools and analysis were undertaken by a Project Advisory Committee (PAC) made up of people with IBD, carers and HCPs.

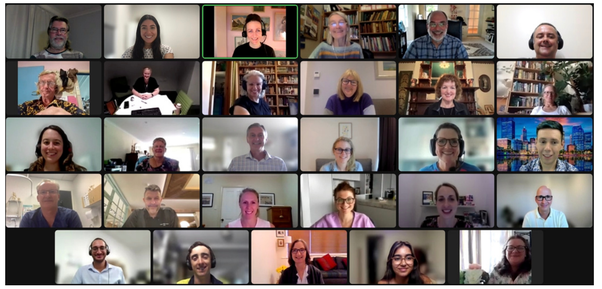
1. National **online survey** for people with IBD, carers and HCPs to collect IBD uncertainties
2. Uncertainties analysed and thematically grouped together, creating **broad topic areas**
3. **Indicative questions** developed, reviewed and evidence checked
4. National online **prioritisation survey** to rank unanswered indicative questions
5. **Final workshop** to prioritise shortlisted questions
6. **Top 10** unanswered research questions for IBD in Australia

Questions about prevention, treatment, symptoms, diagnosis and living with IBD for both paediatric and adult Crohn's disease, ulcerative colitis and IBD unclassified were included, whilst questions about cause, cure and information-seeking were excluded.

Results

890 research questions submitted from **224** participants → **117** summary questions formed and evidence checked → **56** summary questions ranked by **538** participants → **TOP 17** ranked in two discussion workshops with **23** participants → **TOP 10** research priorities for IBD in Australia determined

1. What are the risk factors for developing IBD (e.g. environmental factors, stress, insecticides, vaccines, antibiotics, glandular fever, removed appendix, susceptibility genes)?
2. How can microbiome (bacteria and other organisms) be modified to prevent IBD?
3. How can IBD be prevented (including those with a family history of IBD or genetic risk, and lifestyle factors, such as food and exercise)?
4. How can quality of life be improved for people with IBD (e.g. reduced visits to the toilet, coping with illness and psychological support)?
5. How can an individual's response to specific IBD medications be predicted?
6. How can food cause or prevent IBD symptoms and/or improve IBD disease severity?
7. What are the potential short- and long-term health effects from taking different IBD medications?
8. What is the most effective treatment for maintaining remission in IBD?
9. What is the link between IBD and mental health and are people with IBD adequately screened for mental health conditions?
10. What is the cause of IBD flares and how can they be recognised and avoided?



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Conclusions

The research demonstrates that by using an established methodology, people with IBD, carers and HCPs can be engaged in determining future priority research areas. The top 10 priorities provide evidence to guide policy, researchers, and research funders to focus on the most urgent and relevant needs of consumers and HCPs.

Next Steps

- Launch and create interest and capacity for research in IBD.
- This project will help CCA to make a case to research funders:
  - Governments and Health Departments
  - Philanthropy and scholarship funds
  - Scientists and researchers
  - Consumers and representative groups.
- Help guide CCA grants and scholarships to the targeted top 10 priorities.

To view the project report please visit
https://www.crohnsandcolitis.org.au/research-priorities/
or contact ibdqualityofcare@crohnsandcolitis.org.au

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References

1. PricewaterhouseCoopers Australia. Improving Inflammatory Bowel Disease care across Australia. Melbourne: Crohn's and Colitis Australia; 2013 [cited 2021 17 Aug]. Available from: https://www.crohnsandcolitis.com.au/site/wp-content/uploads/PwC-report-2013.pdf.
2. Busingye D, Pollack A & Chidwick, K. Prevalence of inflammatory bowel disease in the Australian general practice population: A cross-sectional study. PLoS ONE. 2021; 16(5): e0252458. https://doi.org/10.1371/journal.pone.0252458.
3. Studd C, Cameron G, Beswick L, et al. Never underestimate inflammatory bowel disease: High prevalence rates and confirmation of high incidence rates in Australia. JGH Open. 2016; 31(1):81-6. https://doi.org/10.1111/jgh.13050.
4. National Health and Medical Research Council (NHMRC) & Consumer Health Forum. Statement on Consumer and Community involvement in Health and Medical Research. NHMRC 2016 [cited 2021 17 Aug]. Available from: www.nhmrc.gov.au/guidelines/publications/s01.
5. James Lind Alliance Priority Setting Partnerships. JLA Guidebook. United Kingdom 2020 [cited 2021 17 Aug]. Available from: https://www.jla.nihr.ac.uk/jla-guidebook/.